AD_____

Award Number: DAMD17-99-1-9317

TITLE: An Investigation of the Facilitative and Inhibitory Variables Impacting Breast Health Practices in Low-Socioeconomic Status Black Women of African American and Caribbean Descent

PRINCIPAL INVESTIGATOR: Kathryn C. LaSorsa, Ph.D.

CONTRACTING ORGANIZATION: New York University
New York, NY 10012

REPORT DATE: October 2003

TYPE OF REPORT: Annual Summary

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

1. REPORT DATE	2. REPORT TYPE	3. DATES COVERED
October 2003	Annual Summary	15 September 1999 – 14 September 2003

4. TITLE AND SUBTITLE

An Investigation of the Facilitative and Inhibitory Variables Impacting Breast Health Practices in Low-Socioeconomic Status Black Women of African American and Caribbean Descent

5a. CONTRACT NUMBER

5b. GRANT NUMBER
DAMD17-99-1-9317

5c. PROGRAM ELEMENT NUMBER

6. AUTHOR(S)

Kathryn LaSorsa

E-Mail: osp.agency@nyu.edu

5d. PROJECT NUMBER

5e. TASK NUMBER

5f. WORK UNIT NUMBER

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)

New York University
New York, NY 10012

8. PERFORMING ORGANIZATION REPORT NUMBER

9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)
U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

10. SPONSOR/MONITOR'S ACRONYM(S)

11. SPONSOR/MONITOR'S REPORT NUMBER(S)

12. DISTRIBUTION / AVAILABILITY STATEMENT
Approved for Public Release; Distribution Unlimited

13. SUPPLEMENTARY NOTES

14. ABSTRACT

Please see next page.

15. SUBJECT TERMS
Please see next page.

16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
a. REPORT	b. ABSTRACT	c. THIS PAGE			USAMRMC
U	U	U	UU	96	19b. TELEPHONE NUMBER *(include area code)*

14. ABSTRACT

Black women of low-socioeconomic status (SES) demonstrate a high incidence of breast cancer mortality associated with late-state diagnosis. Breast cancer screening, including mammography, breast self-examination, and clinical breast examination, remains the most effective route to early cancer detection. Studies indicate poor adherence to breast cancer screening regimens among low-income minority women. An overall objective of the study is the construction of models that can explain screening practices in low-SES black women. This will be accomplished in two separate waves. In the first wave, facilitators and barriers to breast cancer screening participation among low-SES women of African-American and Caribbean descent will be determined through qualitative interview. This approach intends to provide a voice for the concerns and experiences guiding these women in their screening choices. The current study incorporates an approach – avoidance theoretical framework that considers preventive screening behaviors to be both desirable and aversive. Based on the factors provided by the respondents in the first wave of the study, culturally-sensitive Q-Sort instrumentation will be designed that allow participants to rank order these factors as facilitators or barriers and therefore, provide strength of modesl to explain breast health care practices among low-SES Black women, either as idiopathic to the general population of low-SES Black women or specific to African-American or Caribbean cultural groups.

15. SUBJECT TERMS

Breast cancer screening, mammography, breast self-exam, access to care, psychosocial barriers to care, minority populations

Table of Contents

Introduction

Black women of low-socioeconomic status (SES) demonstrate a higher incidence of breast cancer mortality associated with late-stage diagnosis than White women. Breast cancer screening, including mammography, breast self-examination, and clinical breast examination, remains the most effective route to early detection. Studies indicate poor adherence to breast cancer screening regimens among low-income minority women. An overall objective of the study is the construction of a theoretical model that can explain screening practices in low-SES black women. This will be accomplished in two separate waves. In the first wave, facilitators and barriers to breast cancer-screening participation among low-SES women of African-American and Caribbean descent will be determined through qualitative interview. This approach allows a voice for the concerns and experiences guiding these women in their screening choices. The current study incorporates an approach-avoidance theoretical framework that considers preventive screening behaviors to be both desirable and aversive. Based on the factors provided by respondents on the first wave of the study, a culturally sensitive Q-Sort instrument will be designed that will allow participants to rank order these factors as facilitators or barriers to screening, and therefore, provide a powerful approach to testing the theoretical paradigm. Finally innovative modeling techniques will be applied to determine the strength of emergent models to explain breast health care practices among low-SES Black women, either as idiopathic to the general population or specific to African-American or Caribbean cultural groups.

Report Body

Research accomplishments are presented in a temporal sequence segmented into semesters to provide a description of the evolution of research tasks and the context in which they occurred. Embedded in this sequential structure is a discussion of research accomplishments that fall into four general categories: accomplishments of a formative nature, accomplishments related to pre-doctoral training, accomplishments specific to the approved Statement of Work, and problems associated with completion of tasks specific to the approved Statement of Work.

Semester 1: Fall 1999

Infrastructure Issues

Coinciding with the beginning of this grant, two site-related issues impacted getting the study underway. First, it was the expectation of the Dental School at UMDNJ that my study would be embedded in a larger population-based study proposed by Dr. Theresa J. Jordan. It was this mother grant that provided my access to necessary staff, a research space that would be available to me for the remainder of the study, and the full cooperation of school and department heads. When this grant was not funded, there was no longer any person contractually involved at the site as all support and approval documented in the letters included in my grant proposal were directly related to Dr. Jordan's intended study. Efforts to reestablish infrastructure would need to begin from the very beginning.

At the same time, the Dental School experienced major turnovers in top leadership positions. A great deal of time this semester had to be spent in repeated meetings with top-level people whose familiarity with and approval for the study was required. Major turnovers in

leadership positions prevented efforts to reestablish the infrastructure necessary for beginning the study.

Also as stated in the approved Statement of Work, Internal Review Board clearance was required from both New York University and UMDNJ. The NYU IRB was submitted in October 1999 and conditionally approved in December. The Internal Review Board at New York University granted permission to carry out human subject research conditional on the approval from the Human Subjects Board at UMDNJ. Staff turnover, coupled with the lack of infrastructure at the project site prevented submission of the UMDNJ IRB. Approval and support to carry out the study at the Dental School was required at the clinic-staff level before it could be sought at the Human Subjects Committee level. With site issues at a standstill, attention was turned to other necessary tasks.

Literature Review

The research literature pertinent to the topic of study was updated from several sources. Since the literature compiled thus far related to the initial grant submission in June 1998, updated research studies and government documents needed to be searched for, acquired and reviewed. **Appendix A** lists the updated documents and literature reviewed during the entire course of the present study. While begun in the Fall 1999, this literature update has been an ongoing task throughout the time of this grant.

Data Issues

After being assigned a research space at NYU, I spent three weeks setting up and organizing the space. Tasks included the creation of an extensive filing system, final design and reproduction of all data collection instruments, and setting up a computer with all appropriate software.

Finally, using the Statistical Package for the Social Sciences (SPSS) version 10.0, a dataset and accompanying data dictionary was compiled. Both files represent all demographic and instrument data to be collected for the study. The present study requires a large amount of data-related organization and management. Extensive demographic information as well as variables from four different measurement instruments needed to be identified. In addition, computed variables representing total scores or weighted information were designed. Information regarding measurement level, category labels and missing values became part of the extensive working data dictionary. **Appendix B** contains a copy of the working data dictionary.

In summary, most of the tasks attended to are formative in nature with the exception of completion of required IRB proposals. The approved Statement of Work states that IRB approval would be obtained during this period. Approval was granted by NYU, but the IRB proposal for UMDNJ was completed and not yet submitted at this time due to the issues relating to infrastructure and site personnel discussed above.

Semester 2: Spring 2000

Site Visits

Work began during this semester to reestablish site infrastructure. Multiple visits to UMDNJ under the supervision of my on-site supervisor, Richard L. Montgomery, D.D.S.,

M.P.H. began in Fall 1999 with the goal of understanding the physical layout, systems and procedures of the Dental Clinic, appointment scheduling and patient access to facilitate eventual participant solicitation and data collection. The Dental School serves socially disadvantaged individuals who live in the urban community located in and around Newark, New Jersey. A large portion of those utilizing clinic services are poor and lack health insurance. In addition, they demonstrate a low utilization of preventive health screening. Most previous research on breast cancer screening adherence has targeted women breast health care facilities. Thus, women already engaging to some degree in breast health care are being asked to speak for those women who are not. This site allows an investigation of women not likely present in the breast health care system.

a. Physical Plant

The UMDNJ-New Jersey Dental School is large and complex facility housed within the sprawling Medical Center campus. The Dental School has nine clinics located on two levels off a spacious, glass-domed lobby, which forms the central waiting area. In addition to the clinic space, there are research laboratories, seminar rooms and lecture halls all designed for both teaching and dental health care delivery. Clinics for Oral Diagnosis and Radiology, Oral Surgery, Periodontics, Endodontics, Orthodontics and Pediatric Dentistry are located on the main floor. General and Hospital Dentistry and Fixed and Removable Prosthodontics are housed on the upper level. Research laboratories, consulting areas, a central sterilization facility and faculty offices are located on these two levels, adjacent to the main treatment areas. Additional rooms serving as temporary office space available to faculty and staff are located on both levels. Those patients not receiving emergency or surgical services will be solicited for participation in the study. Thus, I will be soliciting participants from the Oral Diagnosis, Periodontics, Orthodontics

and General Dentistry clinics. Contact with support staff in each of these clinics as well as instruction on how to work within the schedules and procedures of each of these clinics was facilitated through my multiple site visits. In addition, an empty room right off the central waiting area has been identified and provided for use in data collection.

b. Typical patient load and treatment procedures

Approximately 80 percent of the new patients who are registered are accepted by screening faculty, are assigned to a student, accept a treatment plan and enter into dental treatment. A review of the data collected in the clinic's registry database for 1997 listed 2817 women seen at least once in the clinic. Of these, 1324 were 40 years of age or older and 45 percent of the women were black. The clinic, thus, provides access to a substantial population of low-income Black women who are within the age groups targeted for screening.

Prospective patients typically coming into the clinic are assigned to a dental student under the supervision of faculty. Patient screening is the first step in a multi-step process preceding treatment implementation. Medical assessment of the patient takes place in the Oral Diagnosis and Radiology clinic. During the second visit to the General and Hospital Dentistry Clinic, the clinical treatment plan is discussed with the patient. Treatment does not typically begin until their third visit to the clinic. Treatment appointments are usually scheduled during one of two daily teaching blocks, at 12:00 p.m. and 4 p.m. Participants will be solicited at three times during the day; before and after the first block and prior to the second block.

When patients arrive, they register with a treatment receptionist and then move to the central waiting area. The wait is typically long and patients are told to set aside two to three hours per clinic visit. There is nothing to do during this long waiting period, which provides the researcher an opportunity to engage those waiting in the study. Since at any time, patients may

be waiting to register, to be seen for consultation or treatment or waiting to be discharged from various clinics, constant communication between the researcher and the clinic is required so that patients available to the study can be identified. Cooperation and guidance from these various clinic staff in patient availability and access has been assured during the many clinic visits made by myself this semester.

c. *Access to Additional Medical School Resources*

Working with Dr. Richard Montgomery, I made contact with the medical school-computing center and library facility to ensure my access to both resources. After explaining the purpose and scope of my research in the Dental School, I was granted full access to the computing center and limited access to the library. I will be able to use the computer center's wide variety of state of the art statistical, database, presentation and printing services during regular clinic hours. I will have access to all library material onsite only.

d. IRB Protocols

Internal Review Board procedures and protocols in a medical environment differ greatly from those in academic settings. The researcher consulted specifically with on-site persons for advice on putting together the IRB proposal within the dictates of Medical School requirements. The IRB proposal was completed, but it was decided not to submit the material until final approval was received from the appropriate top-level people at the Dental School to come into the clinic and carry out the study. It was the opinion of both myself and the on-site supervisor that clinic-level clearance by top-level staff should precede Human Subject Department clearance.

In summary, these multiple site visits have informed my understanding of Internal Review Board procedures and protocols, the clinic layout and scheduling procedures as well as facilitating communication between myself and those support staff that will be assisting me in access to potential study participants. In addition, I have been cleared to use important computer and library resources.

Staff Training

With the many tasks required of the study including qualitative data collection and transcription, quantitative data collection, entry and analysis, and ongoing literature updating, the need for research assistants became apparent. The search for potential research assistants began in February. Due to the non-paid nature of these positions, undergraduate assistants who were interested in the research process but not highly skilled were sought. As such, extensive training was provided after the two assistants were identified.

I made initial contact with the faculty person in charge of research method coursework and field placement in the College of Arts and Sciences at New York University. After two meetings, three students were presented for consideration. After interviewing these students one student was chosen to do her fieldwork experience on the present grant. I made another visit to Audrey Cohen College and after speaking with a colleague, an additional student who was also required to complete field placement was identified. Both assistants were new to the research process. For over a month, these assistants were trained in the following:

a) How to use research databases, including PsychLit, Sociofile and Medline, to conduct ongoing searches for study-related literature.

b) How to summarize collected research articles using the project's Research Review Summary Sheet

c) How to create study-related databases with Microsoft Access

d) How to do basic data entry into SPSS v.10.0

Databases necessary to organize the study were created in Microsoft Access between March and May. These databases archived the following information:

a) All research articles that had abstracts on file in the research space

b) All articles retrieved and summarized

c) An ongoing list of articles to be retrieved and summarized

d) A bibliography of all government working papers and other documents acquired off related Internet sites

Instrument Development

The largest undertaking for the Spring 2000 was the initial development of an instrument to measure access to and utilization of health care among the study population. The rationale behind this decision emerged from engagement in the ongoing process of literature review. During this process, critical studies were identified, alerting me to dimensions to be targeted in this instrument. This pre-doctoral study is motivated and informed by the discrepancy in breast cancer mortality and levels of screening practices between low-income minorities and other middle, and upper class populations. Several current government initiatives, including the Department of Health and Human Services ongoing initiatives Healthy People 2000 and Healthy People 2010, the DHHS Division of Health Promotion and Disease Prevention's Final Report on "Leading Health Indicators for Healthy People 2010 (1999), and the Institute of Medicine's report entitled "Access to Health Care" (1999) indicate that much of these discrepancies in health prevention behavior and health outcomes can be traced to the discrepancies in health care access

experiences by these underserved populations. Access is being defined as both the utilization and quality of health care as reported by health care consumers (Millman, 1993). The World Health Organization, in an ongoing initiative entitled "Health Systems: Improving Performance (1999,2000) has determined that any agenda to improve health systems for underserved populations must address the issues of *goodness* and *fairness*. Goodness is defined as "the best attainable average level of" of good health (pg. xi). Fairness is defined as "a health system that responds well to everyone, without discrimination" (pg. xi).

The "Leading Health Indicators for Healthy People 2010 Report" (1999) has included access to quality health care in their set of Life Course Determinants and Prevention indicators. The report applies two conceptual frameworks important to the current study. In the field model (Evans and Staddart, 1992) determinants of health, such as access to health care, are predictive of positive health behaviors such as cancer screening and positive health outcomes at the individual and population levels. The life course health development model (Halfron, Sutherland, & Inkelas, 1999) reflects evidence that "health outcomes and health status follow a developmental process in which current health status and outcomes are the product of cumulative inputs across the life span" (pg. 8). According to this model, health determinants such as health care access influence an individual's subsequent life course of preventive behaviors and health outcomes. The current study was designed to tap the factors influencing breast cancer screening that are based on the experiences and concerns of the women in question, and not on variables predetermined by the researcher. It appears, though, that attention to issues of health care access are necessary to provide a full representation of the experiences of these women in a health system that continues to present barriers to quality access and healthy outcomes. Low levels of screening participation and elevated levels of breast cancer mortality in the study population

speak directly to these health care barriers. As such, development of such an instrument began in earnest in early January 2000. Initial efforts were focused on evaluating current literature and government papers on the topic of health care access, both broadly, and as it applies to the study population. Refer to **Appendix A** for a complete list of references. The purpose of this inquiry was to establish those areas of utilization, quality of care, and health outcomes that would inform the initial item pool. Guidance was also provided by Dr. Richard Montgomery, the on-site grant supervisor, whose specialties include survey research in health care and service delivery to underserved urban populations, during two visits to UMDNJ. Subsequent item development began in March. The full instrument is discussed later in the report and referenced in an Appendix at that time.

Pre-doctoral Training

The principal investigator undertook a pre-doctoral training piece independently during this semester. As part of the current study, Q-methods will be employed. Using initial qualitative interviews to compile a list of factors influencing breast cancer screening participation, a culturally sensitive Q-Sort instrument will be developed by the researcher to determine the nature of these facilitators and barriers. A high-level understanding of the methodological and statistical aspects of Q-methods was desired. The questions of interest included:

a) How can Q-methods be applied to test the strength of the theoretical approach-avoidance paradigm as it applies to breast cancer screenig?
b) How do Q-techniques differ from R-techniques?
c) What are the historical and philosophical foundations of Q-methodology?

d) What are the differing approaches to the design of Q-Sorts and the analysis of Q-Sort data, including the benefits and disadvantages of forced vs. free sorting?

e) How can the psychometric rigor of Q-Sorts be evaluated?

Training was facilitated through collection and review of both current literature and classic works in the field of Q-methodology, ongoing participation in Q-method discussion forums on the World Wide Web, and membership in the International Society for Scientific Study of Subjective (ISSSS) to ensure access to archival documents and the Journal of Objective Subjectivity. See **Appendix C** for a complete reference list.

In summary, during Semester 2 of the study (Spring 2000), substantial movement was made in rebuilding infrastructure at the site so that data collection could begin. Again, most of the accomplishments of this semester were formative in nature, including the initial development of health care access instrument, the training of research assistants, the creation of study-related databases, and an important pre-doctoral training piece.

Summer 2000

By the middle of May, contacts with all necessary top-level people at UMDNJ had been completed. The principal investigator was familiar with the surroundings of the Dental School, its policies and procedures and their impact on efforts to acquire subjects and collect data. By the end of May a major problem for the study developed. As someone living with diabetes mellitus, I was taken gravely ill and hospitalized on May 29. Due to an infection of unknown origin, diabetic ketoacidosis set in resulting in severe dehydration, unmanageable potassium levels and

retinal and kidney impairment. Due to the substantial impact on several body systems, recuperation took place over the next two months.

Semester 3: Fall 2000

Resuming work, I was close to total recovery by the beginning of September and returned to school. My absence of several months led to returning to a project that was not yet in place and running. This fact coupled with the need to prepare a first Annual Summary Report by mid-October, led to my decision to contact my DOD Contract Specialist with great concern. The problems encountered in infrastructure rebuilding and due to illness were communicated to the Contract Specialist. It was determined that the deadline for the Annual Summary Report would be extended until mid-January of 2001. In the meantime, efforts to access the site in addition to several formative tasks would continue.

Issues Related to IRB Proposal

A revised IRB was completed in November to reflect changes in the scope of the study. This IRB packet was submitted to Dr. Richard Montgomery for review before submission to the committee. Problems with IRB approval at UMDNJ surfaced in December, when it was announced that the Internal Review Board was embarking on a review and revision of Human Subject policy and procedures. There was a moratorium in place on submission, which is presently being lifted.

Issues Related to Site Infrastructure

All meetings necessary to finalizing issues of infrastructure have taken place. Contacts have been made with top-level individuals, including the appropriate Department Chair and Dean, who have verbally consented to my carrying out the study at the Dental School conditional to IRB approval. This is a positive outcome considering the lack of contractual involvement of any person on staff at the Dental School. The principal investigator has met with all support staff who will be available in my efforts to solicit participants and collect data. A small workspace has been made available to the principal investigator where study-related tasks including data collection can take place.

Instrumentation

Work continued this semester on the development of the Access to Health Care instrument. See **Appendix D** for a copy of this and all study instruments. All items are now designed for the current version of the measure. Future piloting of the instrument may necessitate revisions. Based on a framework employed by Agency for Health Care Research and Quality (AHRQ) in the psychometric testing of their Consumer Assessment of Health Plans System (CHAPS), cognitive testing of the instrument was undertaken in November through the voluntary participation of medical professionals who are colleagues of the principal investigator. Cognitive testing provides assessment through feedback from interviews with medical professionals who are asked to react to the survey questions. According to Forsyth and Lesser (1991), cognitive testing is an effective technique for surveys in the early stages of development. The think-aloud method was employed, in which individuals were asked to verbalize their

thoughts on the individual items as they read and answered each instrument item out loud. Entire questions, words or phases, and response choices that were ambiguous were identified. In addition, respondents were asked to suggest aspects of health care access not tapped in the instrument. As a result, six additional items tapping adherence to physician recommendations for prescribed medication and lifestyle changes were added. Finally, applying the CHAPS framework, it was decided that explicit reference points, such as "currently" or "at the present time" be incorporated into survey items to "standardize the amount of time about which respondents are asked" (AHRQ, 1997).

Pre-Doctoral Training

An additional pre-doctoral training piece was independently undertaken this semester. Qualitative interviews are being conducted for the first wave of data collection. Prior to this training effort, the principal investigator had limited knowledge of qualitative methods. Training took place in a formal doctoral-level qualitative methods course supplemented by immersion in qualitative literature, texts and Web-based documents. See **Appendix E** for qualitative methods references.

Training issues included:

a) An overview of various qualitative methods and techniques.

b) How is a qualitative interview protocol designed?

c) How are qualitative interviews coded and analyzed?

It has been decided that a very loosely structured interview protocol will be utilized. In an effort to conduct an interview that allows the participant's voice (the emic voice) to emerge, the content of most follow-up questions will be driven by the participant's narrative. Using the work

of Padgett (1998) and Morse (1994), decisions regarding data analysis have been finalized. Each interview will be recorded and transcribed. Through several readings, each interview will undergo line-by-line coding, where meaning units will be identified. Meaning units of interest are those pieces of information provided by the participants that describe factors that inhibit or facilitate screening participation. These meaning units will form the basis for items for the Q-Sort measure.

The analysis scheme will utilize "open coding" (Emerson, Fretz, & Shaw, 1995) where the emphasis rests on making sense of participants' experiences with screening as opposed to imposing preexisting or a priori concepts to their narratives. Constant comparative analysis (Padgett, 1998) will be the applied coding method. This method utilizes an iterative approach that begins with inductive meaning making, moves to deductive meaning making and then returns to an inductive approach. Meaning units emerge from the initial coding (inductive). Then one goes back over the data to ensure that it has been coded in a way compatible with these units (deductive). In this way, new codes often emerge (inductive).

To ensure the reliability of coded data, inter-rater consistency will be assessed by calculating a coefficient of correspondence (Cohen, Swerdlik, & Phillips, 1996) between the coding decisions of the principal investigator and a research assistant.

In summary, all work on infrastructure was completed during this semester. Delays in IRB approval have continued as a result of the reworking presently going on in that office at UMDNJ. It is anticipated that the IRB will need one final revision to reflect expected changes in Human Subject procedures and protocol. It is also anticipated that the new IRB system will be in effect shortly at which time the final IRB proposal will promptly be submitted for review. Development of the Access to Health Care Survey has moved very far along. All items have

been constructed. Cognitive testing of the instrument addressed problems with item clarity and construct validity. A second pre-doctoral training piece on Qualitative Methodology was completed. Decisions on design, data collection and data analysis were finalized.

Semester 4: Spring 2001

With the moratorium on IRB proposal submission presently being lifted, it is anticipated that my IRB package will be acted on at the first meeting to take place on March 1, 2001. The IRB package is ready and awaiting submission. Formative work on the study has continued. All study-related databases have been updated during this semester. As part of the ongoing update of research literature, work has been ongoing since January 1 to gather and review up-to-date documents and reports from a wide variety of government agencies. Government resources include: the World Health Organization, Department of Health and Human Services, Institute of Medicine, The Cancer Institute, The National Women's Health Information Center, The Health Information Center for Minority Women, The Office of Minority Health Research, The Agency for Health Care Research and Quality, the CDC's Morbidity and Mortality Weekly Report, The National Health Information Center, and Healthy People 2000 and 2010 initiatives. Documents relating to breast cancer screening, disparities in minority health outcomes, and disparities in minority access to health care have been retrieved and summarized. **Refer to Appendix A for a list of document references.**

Key Research Accomplishments

- Completed and submitted IRB proposal to New York University and received approval conditional on project site approval.
- Completed IRB proposal for submission to UMDNJ-New Jersey Dental School Human Subject Committee (See Report Body for discussion of problems encountered with submission).
- Reestablished infrastructure at project site, UMDNJ-New Jersey Dental School, which became necessary since initial support was embedded in a mother grant that was ultimately not funded. This task included receiving support and clearance to carry out study from top-level staff at the Dental School, becoming familiar with the physical plant of the school and its multiple clinics and workstations, gaining an understanding of the schedules, procedures and protocols of the school, securing work space for data collection and other project-related tasks.
- As an ongoing effort, updated research literature and government document and reports applicable to the study goals have been retrieved and summarized.
- Design and ongoing update of dataset and data dictionary using the Statistical Package for the Social Sciences (SPSS) version 10.0
- Provided comprehensive training in research methods and protocols to two undergraduate research assistants.
- Created all project-related databases using Microsoft Access 2000.
- Development of Access to Health Care Instrument to measure utilization and quality of health care among the study population.

- As a first step to testing the psychometric rigor of the Access to Health Care Instrument, cognitive testing of the instrument was carried out and necessary revisions to the instrument were made.
- Completed pre-doctoral training piece designed to provide a deep understanding of the methodological and statistical aspects of Q-Methods.
- Completed additional pre-doctoral training piece designed to provide a deep understanding of methodological issues involved in interview protocols and procedures, interview coding, analysis and interpretation and data reliability.

Reportable Outcomes

- Development of instrument to assess Access to Health Care.
- Psychometric testing of instrument to assess Access to Health Care.

Conclusions

While substantial site-related problems occurred that influenced the timetable of this research endeavor, much formative movement has been made over the last year. Problems emerged when the mother grant of Dr. Theresa J. Jordan (the pre-doctoral grant supervising mentor) was not funded and expected support for the study was removed. As result, the on-site infrastructure needed to rebuilt from scratch. This was a huge undertaking that required much time and effort on the part of the principal investigator. Impeding this effort was the major turnover in top-level staff at the Dental School during a substantial part of the first year of this grant. Also impacted were efforts to receive IRB approval from the Dental School. When infrastructure was finally in place and the IRB proposal package could be submitted, the Dental School placed a moratorium on all IRB submissions as an overhaul of Human Subjects procedures and protocols for the entire Medical School was implemented. Currently, the moratorium has been lifted and it is anticipated that my IRB package will be acted on at the first meeting to take place on March 1, 2001.

Despite the impact of the above problems on meeting Statement of Work deadlines, many tasks of a formative nature have been addressed and completed. Several important pre-doctoral training pieces were undertaken to increase my knowledge and skill level in two methodological areas significant to the research study, qualitative methods and Q-Methods. The extensive training in research methods and techniques for two undergraduate research assistants was necessitated by the inability to contractually support research staff. As an ongoing effort, all pertinent research literature and government reports have been updated and reviewed. Emerging from this effort, critical studies and government initiatives were identified that provided evidence of the need to broaden the scope of measurement in the study to address access to health care

among the study population. An instrument to measure the utilization and quality of health care experienced by low-income Black women was designed and cognitively tested.

So What

Incorporating Access to Health Care Instrumentation

With a significant proportion of the Dental School patient population lacking health insurance, the quality of and access to health care becomes of vital importance for the present study. Current government initiatives provide evidence that discrepancies in health prevention behavior and health outcomes among poor minority individuals can be traced to the discrepancies in their health care access experiences. Issues of goodness (attaining the best average level of good health) and fairness (a health system that responds well to everyone without discrimination), as conceptualized by the World Health Organization, are currently viewed as essential to any agenda to improve health outcomes and health systems for underserved populations. Measuring access to health care among the study population and examining its intersection with breast cancer screening practices will inform the knowledge base on cancer screening among underserved populations. With much of the current initiatives on health care focused on collecting quantitative data on service usage, attempts to measure the perceptions about quality of health care while identifying problems associated with health care access will imbed issues of breast cancer screening into the proper health system context.

References

Agency for Health Research and Quality (AHRQ). (1998). Consumer Assessment of Health Plan Study (CAHPS). http://www.ahrqu.gov/qual/cahps.

Cohen, R.J., Swerdlik, M.E., & Phillips, S.M. (1996). Psychological testing and assessment: An introduction to tests and measurements. Mountain View, CA: Mayfield Publishing Company.

Emerson, R.M., Fretz, R.I., & Shaw, L.L. (1995). Writing ethnographic fieldnotes. Chicago: University of Chicago Press.

Healthy People 2010 Home Page. http://odphp.osophs.dhhs.gov/pubs/hp2000/2010.

Institute of Medicine (1993). Access to health care in American: Committee on monitoring access to personal health care services. Washington, D.C.: National Academy Press.

Institute of Medicine (1999). Leading health indicators for Healthy People 2010. Washington, D.C.: National Academy Press.

Morse, Janice M. (1994). Critical issues in qualitative research methods. Thousand Oaks, CA: Sage Publications, Inc.

Padgett, D.K. (1998). Qualitative methods in social work research: Challenges and rewards. Thousand Oaks, CA: Sage Publications, Inc.

World Health Organization (2000). The world health report 2000: Health systems: Improving performance.

Annual Summary Report

Appendices

Appendix A: Updated Research Literature and Government Reports

Topic: Breast Cancer Screening Among Minority Women

Bostick, R.M., Sprafka, J.M., Virnig, B.A., & Potter, J.D. (1994). Predictors of cancer prevention attitudes and participation in cancer screening examinations. Preventive Medicine, 23, 816-826.

Caplan, L.S., Lane, D.S., & Grimson, R. (1998). The use of cohort vs repeated cross-sectional sample survey data in monitoring changing breast cancer screening practices. Preventive Medicine, 24, 553-556.

Costanza, M.E. (Guest Editor). (1992). Breast cancer screening in older women: Recommendations, supporting statements, and background papers. Special Issue of Journal of Gerontology.

Curry, S.J., Taplin, S.H., Anderman, C., Barlow, W.E., & McBride, C. (1993). A randomized trial of the impact of risk assessment and feedback on participation in mammography screening. Preventive Medicine, 22, 350-360.

Frazier, E.L., Jiles, R.B., & Mayberry, R. (1996). Use of screening mammography and clinical breast examinations among Black, Hispanic, and White women. Preventive Medicine, 25, 118-125.

Hardy, R.E., Ahmed, N.U., Hargreaves, M.K., & Semenya, K.A. (2000). Difficulty in reaching low-income women for screening mammography. Journal of Health Care for the Poor and Underserved, 11, 45-57.

Lantz, P.M., Richardson, L.C., Sever, L.C., Macklem, D.J., & Henson, R. (2000). Mass screening in low-income populations: The challenges of securing diagnostic and treatment services in a national cancer screening program. Journal of Health Politics, Policy and Law, 25, 451-471.

Lawrence, V.A., Streiner, D., Hazuda, H.P., Naylor, R., Levine, M., & Gafni, A. (1999). A cross-cultural consumer-based decision aid for screening mammography. Preventive Medicine, 30, 200-208.

Mandelblatt, J., Gold, K., O'Malley, A.S., Taylor, K., Cagney, K., Hopkins, J.S., & Kerner, J. (1999). Breast and cervix cancer screening among multiethnic women: Role of age, health, and source of care. Preventive Medicine, 28, 418-425.

Mandelblatt, J., Traxler, M., Lakin, P., Kanetsky, P., & Kao, R. (1993). Targeting breast and cervical cancer screening to elderly poor black women: Who will participate? Preventive Medicine, 22, 20-33.

May, D.S., Lee, N.C., Richardson, L.C., Giustozzi, A.G., & Bobo, J.K. (2000). Mammography and breast cancer detection by race and Hispanic ethnicity: Results from a national program. Cancer Causes and Control, 11, 697-705.

National Cancer Institute. (1997). NIH consensus development conference on breast cancer screening for women ages 40-49: Program and abstracts.

Paskett, E.D., McMahon, K., Tatum, C., Velez, R., Shelton, B., & Case, D.L. (1998). Clinic-based interventions to promote breast and cervical cancer screening. Preventive Medicine, 27, 120-128.

Rajaram, S.S., & Rashidi, A. (1998). Minority women and breast cancer screening: The role of cultural explanatory models. Preventive Medicine, 27, 757-764.

Rakowski, W., Pearlman, D., B.K. Rimer, & Ehrich, B. (1995). Correlates of mammography among women with low and high socioeconomic resources. Preventive Medicine, 24, 149-158.

Saywell, R.M., Champion, V.L., Skinner, C.S., McQuillen, D., Martin, D., & Maraj, M. (1999).

Cost-effectiveness comparison of five interventions to increase mammography screening. Preventive Medicine, 29, 374-382.

Schweitzer, M.E., French, M.T., Ullmann, S.G., McCoy, C.B. (1998). Cost-effectiveness of detecting breast cancer in lower socioeconomic status African American and Hispanic women through mobile mammography services. Medical Care Research and Review, 55, 99-115.

Solomon, L.J., Mickey, R.M., Rairikar, C.J., & Worden, J.K. (1998). Three-year prospective adherence to three breast cancer screening modalities. Preventive Medicine, 27, 781-786.

Slater, J.S., Ha, C.N., Malone, M.E., McGovern, P., Madigan, S.D., & Finnegan, J.R. (1998). A randomized community trial to increase mammography utilization among low-income women living in public housing. Preventive Medicine, 27, 862-870.

Vacek, P.M., Mickey, R.M., & Worden, J.K. (1997). Reliability of self-reported breast screening information in a survey of lower income women. Preventive Medicine, 26, 287-291.

Wu, Y., Weissfeld, J.L., Weinberg, G.B., & Kuller, L.H. (1999). Screening mammography and late-stage breast cancer: A population-based study. Preventive Medicine, 28, 572-578.

Topic: Instrument Development

Agency for Health Research and Quality (AHRQ). (1998). Consumer Assessment of Health Plan Study (CAHPS). http://www.ahrqu.gov/qual/cahps.

Anastasi, A., & Urbina, S. (1997). Psychological Testing (7th Ed.). Upper Saddle River, NJ: Prentice-Hall.

Cohen, R.J., Swerdlik, M.E., & Phillips, S.M. (1996). Psychological testing and assessment: An introduction to tests and measurements. Mountain View, CA: Mayfield Publishing Company.

Committee on Population, Commission on Behavioral and Social Sciences and Education, National Research Council. (1997). Racial and ethnic differences in the health of older Americans. Washington, D.C.: National Academy Press.

Halfon, N., Sutherland, C., & Inkelas, M. (1999). Life course health development: A model for measuring health and selecting indicators. UCLA Center for Healthier Children, Families, and Communities.

Healthy People 2010 Home Page. http://odphp.osophs.dhhs.gov/pubs/hp2000/2010.

Kaiser Commission (2000). Health insurance coverage and access to care among African Americans. www.kff.org.

Institute of Medicine (1993). Access to health care in American: Committee on monitoring access to personal health care services. Washington, D.C.: National Academy Press.

Institute of Medicine (1999). Leading health indicators for Healthy People 2010. Washington, D.C.: National Academy Press.

Office of Minority Health. (1999). Closing the gap: The problem of accessing health care.

Schoenbaum, M., & Waidmann, T. (1997). Race, socioeconomic status, and health: Accounting for race differences in health. Journals of Gerontology, 52B, 61-73.

Weinick, Zuvekas, & Cohen. (2000). Racial and ethnic differences in access to and use of health care services, 1977 to 1996. Medical Care Research and Review, 57, 36-54.

World Health Organization (2000). The world health report 2000: Health systems: Improving performance.

Appendix B: Excerpt from Data Dictionary

Subject Code	1	*Code_id*	Label information
Length		8	
Variable Label		None	
Missing Values		None	
Measure		Scale	
Date of Interview	2	date_int	
Length		XX/XX/XX	
Variable Label		None	
Missing Values		99	
Respondent Source	3	source	
Length		8	
Variable Label		1	Current patient (presently receiving trtment)
		2	Screening patient (not receiving trtment)
		3	Emergency patient
Measure		Nominal	
Date of Birth	4	Birthdat	
Length		XX/XX/XX	
Variable Label		None	
Missing Values		99	
Place of Birth	5	birthplce	
Length		8	
Variable Label		TO BE	CODED
Measure		Nominal	
Current Residence	6	curr_res	
Length		8	
Variable Label		TO BE	CODED
Measure		Nominal	
How long lived there	7	longlive	
Length		8	

Variable Label		None	
Measure		Scale	
Caribbean Is.	9	carib_is	
Length		8	
Variable Label		TO BE	
Measure		Nominal	
ESL	10	esl	
Length		11	
Variable Label		1	No
		2	Yes
Measure		Nominal	
Other Language	11	lang	
Length		8	
Variable Label		TO BE	
Measure		Nominal	
Language spoken	12	langspk	
Length		8	
Variable Label		1	English
		2	Spanish
		3	French (all variations)
		4	Creole
		5	Other
Measure		Nominal	
Language write	13	langwrit	
Length		8	
Variable Label		1	English
		2	Spanish
		3	French (all variations)
		4	Creole
		5	Other
Measure		Nominal	
Language read	14	langread	
Length		8	
Variable Label		1	English

		2	Spanish
		3	French (all variations)
		4	Creole
		5	Other
Measure		Nominal	
News source	15	news	
Length		8	
Variable Label			TO BE CODED
Measure		Nominal	
Community Info	16	commserv	
Length		8	
Variable Label			TO BE CODED
Measure		Nominal	
Community Service	17	commserv	
Source			
Length		8	
Variable Label			TO BE CODED
Measure		Nominal	
Med'l Serv. Source	18	medlserv	
Length		8	
Variable Label			TO BE CODED
Measure		Nominal	
Marital Status	19	marital	
Length		8	
Variable Label		1	Single (Never Married)
		2	Married/Partner
		3	Separated
		4	Divorced
		5	Widowed
Measure		Nominal	
No. of children	20	Kids	
Length		8	
Variable Labels		None	
Measure		Scale	

No. of births	21	Births	
Length		8	
Variable Labels		None	
Measure		Scale	
Religion	22	religion	
Length		8	
Variable Label		1	Roman Catholic
		2	Southern Baptist
		3	Jehovah Witness
Nominal			REST TO BE CODED
Strong Relig. Faith	23	Religbel	
Length		8	
Variable Label		0	No Opinion
		1	Strongly Disagree
		2	Disagree
		3	Agree
Ordinal		4	Strongly Agree
Spiritual Person	24	Spiritual	
Length		8	
Variable Label		0	No Opinion
		1	SD
		2	D
		3	A
Ordinal		4	SA
Present Occupation	25	Occup	
Length		8	
Variable Label			TO BE CODED
Nominal			
Time in Occup	26	Timeocc	
Length	8		
Variable Label			NONE
Interval			

Appendix C: Q-Methods References

Block, J. (1962). A comparison of the forced and the unforced Q-sorting procedures. Educational and Psychological Measurement, 68, 481-493.

Brown, S.R. (1997). The history and principles of Q methodology in psychology and the social sciences. http://facstaff.uww.edu/cottlec/Qarchive/Bps.html.

Brown, S.R. (1996). Q methodology as a foundation for the science of subjectivity. http://facstaff.uww.edu/cottlec/Qarchive.science/html

Brown, S.R. (1996). Q methodology and qualitative research. Qualitative Health Research, 6, 561-567.

Brown, S.R. (1991). A Q methodological tutorial. http://facstaff.uww.edu/Qarchive/Primer.html

Brown, S.R. (1986). Q technique and method: Principles and procedures. In W.D. Berry & M.S. Lewis-Beck (Eds.), New tools for social scientists (pp. 57-76). Beverly Hills, CA: Sage.

Dennis, K.E. (1986). Q methodology: Relevance and application in nursing research. Advances in Nursing Science, 8, 6-17.

Gordon, L.V., & Hofmann, R.J. (1968). The forced-choice test as a structured Q-sort. Educational and Psychological Measurement, 28, 11-3-1110.

Guilford, J.P. (1963). Preparation of item scores for the correlations between persons in a Q factor analysis. Educational and Psychological Research, 23, 13-23.

Hayslip, B. (1984). Idiographic assessment of the self in the aged: A case for the use of the Q-sort. International Journal of Aging and Human Development, 20, 293-311.

Kerlinger, F.N., & Kaya, E. (1959). The construction and factor analytic validation of scales to measure attitudes towards education. Educational and Psychological Measurement, 1, 13-29.

Kitzinger, C., & Stainton Rogers, R. (1985). A Q-methodological study of lesbian identities. European Journal of Social Psychology, 15, 167-187.

Neff, W.S., & Cohen, J. (1967). A method for the analysis of the structure and internal consistency of Q-Sort arrays. Psychological Bulletin, 68, 361-368.

Rinn, J.L. (1961). Q methodology: An application to group phenomena. Educational and Psychological Measurement, 21, 315-329.

Stephenson, W. (1977). Factors as operant subjectivity. Operant Subjectivity, 1, 3-16.

Stephenson, W. (1953). The study of behavior: Q-technique and its methodology. Chicago, IL: University of Chicago Press.

Appendix D: All Instrumentation

I. DEMOGRAPHIC INFORMATION AND ACCESS TO HEALTH CARE SURVEY

Code ID: _____ ***Date:*** _____

Clinician ID: _____

Respondent Source
- Currently being screened for dental treatment _____
- Current dental clinic patient (receiving dental care) _____
- Dental screening patient (treatment not yet begun) _____
- Emergency dental patient _____

1. Date of Birth _____

2. Place of Birth _____

3. Where do you currently live? _____

4. How long have you lived there? _____

5. How long have you lived in the United States? _____

6. What is your ethnicity:
   - African-American _____
   - Caribbean (state which Island) _____
   - Other (specify) _____

7. Is English your Second Language (ESL) Yes _____ No _____

8. What other languages do you speak? _____

9. When you speak, what is your primary language? _____

10. When you write, what is your primary language? _____

11. When you read, what is your primary language? _____

12. What is your main source of news? _____

13. What are your main sources of information about your community? _____

14. What are your main sources of information about the services in your community?

_____

15. How do you know where to go for medical services?

_____

16. What is your marital status?

Single (never married) _____ Divorced _____
Married _____ Widowed _____
Separated _____

17. How many children do you have? _____

18. Number of births: _____

19. What is your Religious affiliation? _____ _____

I will read you a statement. Please pick the choice you most agree with:

20. I consider myself to have a very strong religious faith:

Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

21. I am a very spiritual person:

Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

22. What is your present occupation? _____

23. How long have you done this work? _____

24. Indicate your highest level of education:

Grades 1-8_____ Some College _____
Some High School _____ College Graduate _____
High School graduate _____ Graduate school _____
Technical or vocational school _____

25. What is the number of people living in your immediate household? _____

26. Now I am going to ask you who they are:

Spouse/partner _____
Children (how many) _____
Dependent children _____
Non-dependent children _____
Parents (how many) _____
Other (specify) _____

27. What is the total amount of your individual monthly wages, not including benefits (check off choice that applies):

$0.00 - $500.00 _____
$501.00 - $1,000.00 _____
$1,001.00 - $1,500.00 _____
$1,501.00 - $2,000.00 _____
$2,001.00 - $2,500.00 _____
$2,501.00 - $3,000.00 _____
More than $3,000.00 _____

28. What is the total amount of your household monthly wages, not including benefits? (check off choice that applies)

$0.00 - $500.00 _____
$501.00 - $1,000.00 _____
$1,001.00 - $1,500.00 _____
$1,501.00 - $2,000.00 _____
$2,001.00 - $2,500.00 _____
$2,501.00 - $3,000.00 _____
$3,001.00 - $3,500.00 _____
$3,501.00 - $4,000.00 _____
More than $4,000.00 _____

29. Do you receive any of the following benefits:

Retirement or pension benefits _____
Social Security Pension (SS) _____
Public assistance _____
SSI _____
Social Security Disability (SSD) _____
Veteran's Benefits _____
Unemployment Insurance _____
AFDC _____
Medicaid _____
Medicare _____
Any other benefits (specify) _____

30. Do you have health insurance at this time? Yes ____ No _____

(a) If yes, what kind _____
(b) If yes, who is the insured? _____

(c) If yes, how long in this plan _____

31. Think back over the last year about the different medical services you received. In the last year have you:

Seen a doctor	Yes _____ No _____
Had a physical examination	Yes _____ No _____
Seen a gynecologist	Yes _____ No _____
Seen a dentist	Yes _____ No _____
Seen a nurse practitioner	Yes _____ No _____
Seen a healer	Yes _____ No _____
Seen a chiropractor	Yes _____ No _____
Seen an acupuncturist	Yes _____ No _____
Seen a homeopathic	Yes _____ No _____
Seen an herbalist	Yes _____ No _____
Seen a hypnotist	Yes _____ No _____

32. Overall, how satisfied are you with the medical services you receive:

Very satisfied _____
Satisfied _____
Somewhat satisfied _____
No Opinion _____
Somewhat dissatisfied _____
Dissatisfied _____
Very dissatisfied _____

33. What is the biggest problem in getting a doctor's appointment?

(Possible prompts):
Contacting the medical office _____
Getting through to someone I can speak to _____
Getting an appointment that fits my schedule _____

34. What is the biggest problem in keeping a doctor's appointment?

(Possible prompts):
Sudden change in schedule _____
Getting to the medical office _____
Finding childcare _____

35. What is the biggest problem when attending the doctor's appointment?

(Possible prompts)
Waiting to be seen by the medical professional _____
Being sent to other doctors for additional evaluation _____
Filling out all the paperwork _____
Paying for the medical services _____

36. Do you have a chronic illness? Yes _____ No _____

37. What type of chronic illness do you have? (List all) _____

38. Do you take medication for your chronic illness at the present time? Yes _____ No _____

39. What kind of medications do you take for your chronic illness? (List all)

_____

_____

40. How satisfied are you with the medical care you get for chronic disease?

Very satisfied	_____
Satisfied	_____
Somewhat satisfied	_____
No opinion	_____
Somewhat dissatisfied	_____
Dissatisfied	_____
Very dissatisfied	_____

41. What are some factors that might keep you from using medical services when you need them? List any that apply.

_____

_____

_____

42. What are some factors that encourage you to use medical services when you need them? List any that apply.

_____

_____

_____

43. What do you like most about the medical care you receive?

_____

_____

44. What do you like least about the medical care you receive?

_____

_____

45. How did you get to your appointment today?

_____

46. How do you usually get to your medical appointments?

_____

47. Do you usually travel to medical appointments:
From your home _____
From your job _____
Other (specify) _____

48. Do you go to different locations for different medical services? Yes _____ No _____

49. Do you know if there is a health clinic within close distance to you? Yes _____ No _____

50. If yes, how often do you use the services there:
Most of the time _____
Some of the time _____
Rarely _____
Never _____

51. How would you rate your travel to and from medical appointments:
Very easy _____
Easy _____
Difficult _____
Very difficult _____

52. Do you have any limitations or handicaps that keep you from getting medical care when you need it? Yes _____ No _____ If yes, explain:
_____
_____

Please tell me how much you agree with the following statements:
53. I trust my health care providers to give me the proper medical care:
Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

54. I trust my health care providers when they make suggestions on how I can best take care of myself:
Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

55. I trust my health care providers when they prescribe medication for me:
Strongly agree _____
Agree _____

No opinion _____
Disagree _____
Strongly disagree _____

I would like you to fill in the blank:
56. I would feel better about my medical care if:

_____
_____

57. I would like you to fill in the blank:
I would feel better about my medical care if my health care provider would:

_____
_____

58. When my health care provider prescribes medication for me, I

(a) Closely follow their instructions:
Always_____ Usually _____ Sometimes _____ Never _____

(b) Fill my prescription:
Always_____ Usually _____ Sometimes _____ Never _____

(c) Take the entire prescription
Always_____ Usually _____ Sometimes _____ Never _____

(d) Trust that the medication will make me feel better:
Always_____ Usually _____ Sometimes _____ Never _____

(e) Worry that the medication will have side effects:
Always_____ Usually _____ Sometimes _____ Never _____

59. When my health care provider makes recommendations about how I can improve my health, I:

(a) Closely follow their instructions:
Always_____ Usually _____ Sometimes _____ Never _____

(b) Agree with their recommendations:
Always_____ Usually _____ Sometimes _____ Never _____

(c) Understand their recommendations:
Always_____ Usually _____ Sometimes _____ Never _____

(d) Trust their recommendations:
Always_____ Usually _____ Sometimes _____ Never _____

60. When I do not follow my health care providers' recommendations, it is usually because:

_____
_____
_____

61. When I do follow my health care providers' recommendations, it is usually because:_____

_____

_____

62. In the last 12 months, how many times did you go to the emergency room for medical care:

None _____ Fill in number of times _____

63. In the last twelve months, not counting visits to the emergency room, how many times have you gone to a doctor's office or clinic:

List number of times _____

64. In the last twelve months, my health care plan caused delays in my health care:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly disagree _____

65. When I go to see a doctor they usually explain things to me in a way that I can understand:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly disagree _____

66. When I go to see a doctor they usually treat me with respect:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly disagree _____

67. When I go see a doctor they usually listen carefully to what I have to say:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly disagree _____

II. INTENT TO BREAST CANCER SCREEN

We are very interested in learning about your thoughts on breast cancer screening. Please respond to each statement honestly. There are no right or wrong answers. List your level of agreement with each statement using the following scale:

1 Strongly Disagree	2 Disagree	3 No Opinion	4 Agree	5 Strongly Agree

1) I plan on having a mammogram sometime next year. _____

2) I plan on performing breast self-examination sometime next year. _____

3) I plan on performing breast self-examination several times next year. _____

4) I haven't really thought about having a mammogram this coming year. _____

5) I plan on performing breast self-examination once a month. _____

6) I have no intention of scheduling a mammogram this coming year. _____

6) I haven't really thought about performing breast self-examination in the future. _____

7) I plan on having a breast examination done by a health care professional sometime next year. _____

8) I have no intention of performing breast self-examination in the coming year. _____

9) I haven't really thought about scheduling a breast examination in the future. _____

10) I have no intention of scheduling a breast examination in the coming year. _____

III. SCREENING BELIEFS SCALE (Champion & Scott, 1997)

Please list your level of agreement with each statement using the following scale:

1	2	3	4	5
Strongly Disagree	***Disagree***	***No Opinion***	***Agree***	***Strongly Agree***

Mammogram:

1) Having a mammography will help me find breast lumps early.

_____

2) I am afraid to find out there is something wrong when I have a mammogram.

_____

3) I cannot remember to schedule an appointment for a mammogram.

_____

4) Having a mammogram will decrease my chances of dying from breast cancer.

_____

5) Having a mammogram costs too much money.

_____

6) People doing the mammogram are rude to women.

_____

7) If I find a lump early through mammogram my treatment for breast cancer may not be as bad.

_____

8) Having a mammogram would expose me to unnecessary radiation.

_____

9) Having a mammogram would be too embarrassing.

_____

10) Having a mammogram is the best way for me to find a very small breast lump.

_____

11) I have other problems more important than getting a mammogram.

_____

12) Having a mammogram would take too much time.

_____

13) It is difficult to get transportation for a mammogram.

_____

14) Having a mammogram would be painful.

_____

15) I don't know how to go about scheduling a mammogram.

_____

16) It is difficult to get childcare so I can get a mammogram.

_____

17) I am afraid to have a mammogram because I don't understand what will be done.

_____

Breast self-examination:

1) When I do breast self-exam I am doing something to take care of myself.

_____

2) Breast self-exam is embarrassing to me.

_____

3) I do not feel I can do breast examination correctly.

_____

4) If I find a lump early through breast exam, my treatment for breast cancer may not be as bad. _____

5) Breast self-exam is not necessary if I have a routine mammogram.

_____

6) Breast self-exam takes too much time.

_____

7) My breasts are too large for me to complete breast self-examination.

_____

8) Completing breast self-exam each month may help me to find breast lumps early.

_____

9) It is hard to remember to do breast self-exam.

_____

10) Breast self-exam is not necessary if you have a breast exam done by a health care provider.

_____

11) My breasts are too lumpy for me to complete breast examination.

_____

12) Completing breast self exam each month may decrease my chances of dying from breast cancer.

_____

13) Doing breast self-exam will make me worry about what is wrong with my breast.

_____

14) I don't have enough privacy to do breast self-examination.

_____

15) I have other problems more important than doing breast self-examination.

_____

16) I know how to perform breast self-examination.

_____

17) I am able to find a breast lump the size of a pea.

_____

18) I can perform breast self-examination correctly.

_____

19) I could find a breast lump by performing breast self-examination.

_____

20) I am able to find a breast lump which is the size of a quarter.

_____

21) I am able to find a breast lump which is the size of a dime.

_____

22) I am sure of the steps to follow for doing breast self-examination.

_____

23) I am able to tell something is wrong with my breasts when doing breast self-examination

_____

24) I am able to tell something is wrong with my breasts by looking in the mirror.

_____

25) I can use the correct part of my fingers when examining by breasts.

_____

III. BREAST CANCER SCREENING PRACTICES
(Saint-Germain & Longman, 1993)

We are very interested in learning about your experiences with breast cancer screening. Please answer each question honestly. There are no right or wrong answers to these questions.

1) Have you ever had a mammogram? **Yes**_____ **No** _____

2) Have you had at least two mammograms? **Yes** _____ **No** _____

3) Have you had at least three mammograms? **Yes** _____ **No** _____

4) Have you had two mammograms in the past two years? **Yes** _____ **No** _____

5) Have you had three mammograms in the past three years? **Yes** _____ **No** _____

6) Have you ever had a breast examination by a health care provider? **Yes** _____ **No** _____

7) Have you had a breast examination in the last year? **Yes** _____ **No** _____

8) Have you ever done a breast self-examination? **Yes** _____ **No** _____

9) Did you perform a breast self-exam in the last year? **Yes** _____ **No** _____

10) On average, how many times per year do you perform breast self-examination.

Yes _____ **No** _____

Appendix F: References on Qualitative Methods

Emerson, R.M., Fretz, R.I., & Shaw, L.L. (1995). Writing ethnographic fieldnotes. Chicago: University of Chicago Press.

Morse, Janice M. (1994). Critical issues in qualitative research methods. Thousand Oaks, CA: Sage Publications, Inc.

Padgett, D.K. (1998). Qualitative methods in social work research: Challenges and rewards. Thousand Oaks, CA: Sage Publications, Inc.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA, Sage Publications, Inc.

Report Body

Research accomplishments are presented in a temporal sequence to provide a description of the evolution of research tasks and the context in which they occurred. Embedded in this sequential structure is a discussion of research accomplishments that fall into two general categories: infrastructure and IRB issues and accomplishments of a formative nature.

I. Infrastructure and IRB Issues

Coinciding with the beginning of this grant, two site-related issues impacted getting the study underway. First, it was the expectation of the Dental School at the University of Medicine and Dentistry of New Jersey (UMDNJ) that my study would be embedded in a larger population-based study proposed by Dr. Theresa J. Jordan. It was this mother grant that provided my access to necessary staff, a research space that would be available to me for the remainder of the study, and the full cooperation of school and department heads. When this population-based grant was not funded, there was no longer any person contractually involved at the site as all support and approval documented in the letters included in my grant proposal were directly related to Dr. Jordan's intended study. Efforts to reestablish infrastructure would need to begin from the very beginning. At the same time, the Dental School experience major turnover in top leadership positions. It was necessary to hold repeated meetings with top-level people whose familiarity with and approval for the study was required. A great deal of time during all of year one and a portion of year two were taken up in these tasks. Going into the current report period, these two tasks were successfully addressed.

Also as stated in the approved Statement of Work, Internal Review Board clearance was required from both New York University and UMDNJ. The NYU IRB has been submitted and

confused as to the actual forces preventing me from submitting and realize that much time has passed and I still have not begun data collection.

As far as my NYU IRB, I submitted an annual continuation packet to NYU on February 5th. NYU had previously granted approval pending approval from UMDNJ. The most current packet was approved pending approval from UMDNJ and also asked for two slight revisions, which were made and resubmitted. I await hearing from the Office of Sponsored Research at NYU.

II. Accomplishments of a Formative Nature

Three tasks were performed this past year that are of a formative nature. The protocol for the qualitative interviews was developed, all quantitative instruments were piloted, the SPSS dataset was modified to address any modification made to survey items, and my literature was updated to include current articles in my topic area as well as consideration of the current controversy surrounding the efficacy of mammography.

Development and Piloting of Qualitative Interview Protocol:

The qualitative interviews will be the first phase of data collection. In order to allow the experiences of respondents regarding breast health care practices to emerge, a semi-structured open-ended format will be used. The protocol places certain structures on the content of the interview, while allowing the researcher to apply prompts to elucidate the respondent's narrative. Refer to **Appendix A** for the Research Interview Protocol. In November 2001, this protocol was piloted on three women to assess the clarity of the questions. Three Black women working in the principal investigator's community volunteered to sit with the reviewer and answer these questions. They were instructed, at the onset, to please let the interviewer know when a question

decided that we would follow this course of action. Nothing would change in terms of my patient population, but the IRB would reside at the School of Public Health. It was decided that both Dr. Montgomery and myself would meet with appropriate personnel at the School of Public Health to receive permission and discuss any changes required from my existing IRB packet.

Unfortunately, over the course of the summer that meeting never took place despite my repeated communications to Dr. Montgomery. By the end of the summer, with the Dental School now closed until the fall, Dr. Montgomery informed me that things had eased at the Dental School and with my own adjustments made to the patient records issue, I'd be able now to submit to the Dental School as originally planned. Meetings were scheduled for September 2001 to address any changes required of my IRB packet. With the occurrences on 9/11, many of these meetings needed to be rescheduled several times throughout the fall. At the same time, Dr. Montgomery became unavailable often through the fall of 2001 and I have since attributed that to fallout from 9/11.

Towards the end of the fall, Dr. Montgomery suddenly notified me that prior to IRB submission, I would need to pilot my instruments and make any necessary revisions to them. He wanted to be able to go to Dental School personnel with evidence of my being able to start data collection immediately upon IRB approval. My efforts at piloting instruments had begun prior to this and will be discussed in the next section. With the beginning of 2002, all piloting tasks were complete, but I still did not receive word regarding IRB submission. While waiting, I downloaded all IRB documentation from the UMDNJ website and rewrote my IRB packet because a year had gone by and I knew I needed to update my forms. Dr. Montgomery told me that once submitted, the IRB would turnover in three days. It appears that I would get an automatic exemption from UMDNJ as my study is viewed by the institution as a non-invasive survey design. As I prepare this report I must say that I still await word from Dr. Montgomery on IRB submission. I am

conditionally approved twice annually pending approval from UMDNJ. For site-related reasons, the principal investigator has not been able to submit a packet or receive approval from UMDNJ. This has continued to be a great source of frustration.

First, there was an overhaul of IRB protocol at UMDNJ, which caused the freezing of any IRB submissions. This moratorium was lifted around 2/01. For the next 3-4 months I awaited word from my on-site mentor, Dr. Richard Montgomery, that my completed IRB packet could finally be submitted for approval. Then, prior to the end of the Spring semester, my on-site mentor informed me that the Dental School was no longer allowing studies requiring the abstraction of medical records to be approved or conducted. They were also less than enthusiastic, suddenly, about any IRB approval for studies conducted by outside researchers. On June 25th, I contacted my contract specialist at DOD, Kathy Dunn, to apprise her of these issues via email. I initially required access to patient records for two purposes: 1) to access information required for exclusionary criteria of potential participants; 2) for information regarding general medical health and access to health care. This dilemma was addressed in two ways. First, because I had developed an instrument to measure access to health care in the previous funding year, I no longer needed patient records to access this information. I also developed a quick patient criteria form that would easily detect those women who were to be excluded from my study (exclusionary criteria include age less than 40 and a family history of breast cancer). I now no longer needed to access patient records. Second, UMDNJ was accredited in May 2001 to open a new School of Public Health, where my on-site mentor was given a joint appointment as Associate Professor. Considering the social science and epidemiological orientation of my study, it seemed appropriate now to channel my IRB proposal through the School of Public Health. In June 2001, I met with both Dr. Jordan (my supervising mentor) and Dr. Montgomery (my on-site mentor) and it was

was either unclear or not important to their breast cancer screening experiences. See **Appendix B** for Summary of Interview Pilot. At the same time, the interviewer noted any questions that were eliciting only yes/no types of responses. The time it took to conduct the interview was also noted. It is the intent of the investigator to not go much beyond 40-45 minutes in length to ensure that the respondent is engaged in the interview in a way that promotes valid data collection. As noted in Appendix B, the interview protocol provided in **Appendix A** reflected any modifications made as a result of this piloting and represents the current version of the protocol.

Piloting of Quantitative Instruments:

The next task to be reported was the piloting of the quantitative instruments. Four quantitative self-report measures will be used in the study. Refer to **Appendix C** for copies of current instruments. Three of them are existing measures located in the literature. They include: Intent to Breast Cancer Screen (modified from Saint-Germain & Longman, 1993), Screening Beliefs Scale (Champion & Scott, 1997), and Breast Cancer Screening Practices (Saint-Germain & Longman, 1993). One measure was developed by the principal investigator for the current study and is called the Access to Health Care Survey. The purpose of this survey is to gather information regarding factors that impact access to health care among low-income underserved populations.

The rationale behind this decision emerged in Spring 200 from engagement in the ongoing process of literature review. During this process, critical studies were identified, alerting me to dimensions to be targeted in this instrument. This pre-doctoral study is motivated and informed by the discrepancy in breast cancer mortality and levels of screening practices between low-income minorities and other middle, and upper class populations. Several current government initiates, including the Department of Health and Human Services ongoing Health People 2000 and Health People 2010, the DHHS Division of Health Promotion and Disease Prevention's Final Report on

"Leading Health Indicators for Healthy People 2010 (1999) indicated that much of these discrepancies in health prevention behavior and health outcomes can be traced to the discrepancies in health care access experienced by underserved populations. As such, development of this instrument began in early January 2000. The full instrument was completed in its tentative version prior to this year and piloting of this instrument occurred in Summer 2001. Cognitive testing of the instrument among medical professionals was undertaken last year and this year, the instrument was piloted on a small number of women for question clarity and content.

Three women agreed to sit down at separate times with the investigator to review the content of the Access to Health Care Survey. All women were white, middle class females living in New York City. At the time of piloting, the investigator was unable to access low-income women of color. These women were asked to listen to each question and provide a response. They were told that in doing so, to please pay special attention to three questions: 1) Is this question unclear; 2) Would you change anything about the response choices to these questions; and 3) Can you think of any questions that you believe should have been asked but weren't.

As a result of this piloting, several changes were made to the instrument. These changes fall basically in two areas: additional items were added, and response choices for several existing items were modified. The current version of this scale now contains 74 items as opposed to the old version with 67 items. Item 36 was added, "Do you have any problems with your health coverage"; after two women volunteered information regarding this when answering item 35. Item 48 was added, "How much average time does a medical appointment take from the moment you leave for the appointment to the moment you return?" It was decided that cost in time should be tapped as well as cost in dollars. Item 49 was added, "Besides the cost of the medical visit, on average, what is the financial cost to you to get to an appointment?" (Prompts include: carfare, bus

or train fare, childcare, lost time from work). This item was added after one woman pointed out that costs incurred could go beyond any payment for services rendered. Item 63 was added, "I would feel better about my medical care if my health insurance carrier would....". Two other existing items ask respondents to fill in the blank to "I would feel better about my medical care if..." or "I would feel better about my medical care if my health care provider would...." Two women provided information on health insurance carrier to second item, so item 63 was added to get at health insurance issues. Finally, Item 73 was added, "When I go for medical care, the office staff usually treats me with respect" after remarks about the medical staff were referred to when interviewer asked about respect of medical doctor.

Several changes in item response choices also resulted from this pilot. Item 30 now asks how long one has been on their current health care plan. Items 33-35 now include "None" and "Other" as additional response choices. For item 35, "What is the biggest problem when attending the doctor's appointment?", "being sent for additional lab work" and "problems with health insurance" were added as additional response choices. Item 46, "How did you get to your appointment today?", now provides specific response choices that include: "drove myself", "cab", "bus", "train", "got a ride", "walked", "ambulette", or "other".

The same three women also participated in a pilot of the three existing measures to be used in the study. Only the Screening Beliefs Scale (Champion & Scott, 1997) was modified. Under the items related to mammography, item 11 stated, "I have other problems more important than getting a mammogram". Two women reported this item to be unclear and it was modified to read, "There are other things in my life more important than getting a mammogram." To further tap this concept, item 18 was added, "Getting a mammogram every year is a high priority for me." Under breast self-examination, item 7 was changed to "My breasts are too large for me to perform breast

self-examination correctly". The word "complete" was changed to "perform" and the word "correctly" was added for clarity. Several items use the word "would", such as "...would be too embarrassing" or "...would be too painful". One woman suggested changing this word to "can". This change was made. Finally, two women said that the response choice "No Opinion" did not seem to fit with the items and suggested it be replaced with "Not Sure". This change was made as well.

Two ongoing tasks have continued this year. First, the dataset created during the first year of the grant has been modified to reflect changes to all quantitative instruments. Second, the literature has been updated to stay abreast of current research, particularly in light of the current controversy surrounding the efficacy of the mammography.

Key Research Accomplishments

1) Completed and submitted the annual IRB proposal to New York University and received approval conditional on project site approval and two minor revisions that were submitted.

2) Completed a new IRB proposal for UMDNJ and still awaiting permission to submit.

3) Developed qualitative interview protocol.

4) Piloted qualitative interview protocol.

5) Piloted all quantitative instruments and made required revisions.

6) Updated dataset and data dictionary to reflect instrument modification.

7) Acquired and summarized latest literature pertaining to study topic.

Reportable Outcomes

1) Development of qualitative interview protocol.

2) Piloting of qualitative interview protocol.

3) Piloting of quantitative instruments

Conclusions

Forces at the study site continue to prevent submission of the UMDNJ IRB. This continues to be a major stumbling block towards the beginning of data collection and a continuing source of frustration for the principal investigator. Dr. Richard Montgomery has recently stated that the IRB packet will be accepted for submission within the next several weeks. A turnaround of three days is anticipated for approval, as the survey design nature of this study, along with the fact that patient records will not need to be accessed, will result in an exception status. This is promising news, but with the delay in approval extending into the second year of the grant, it is crucial that this problem be addressed immediately.

With these current IRB issues, data collection efforts continue to be delayed and the principal investigator has not been able to meet Statement of Work deadlines. Time this year, then, has been spent on tasks of a formative nature. It is to be clear that despite not being able to begin data collection, the principal investigator has sought to engage in other tasks necessary of the grant. There is work going on from this end. As already reported, qualitative and quantitative measurements have been developed and piloted. The qualitative interview protocol is now in place and all quantitative instruments are ready for data collection to commence. Ongoing efforts to update pertinent literature as well as the study dataset have also continued.

Upon resolution of IRB issues, the principal investigator will be able to spend 3-4 full days per week in active data collection efforts.

References

Agency for Health Research and Quality (AHRQ). (1998). Consumer Assessment of Health Plan Study (CAHPS). http://www.ahrqu.gov/qual/cahps.

Health People 2010 Home Page. http://odphp.osophs.dhhs.gov/pubs/hp2000/2010.

Institute of Medicine (1999). Leading health indicators for Healthy People 2010. Washington, D.C.: National Academy Press.

Annual Summary Report

Appendices

Appendix A: Research Interview Protocol

1) Personal information
    a) How old are you?
    b) What is your country of origin? How long have you lived in this country? In New Jersey?
    c) Are you married? Do you have any children?
2) Knowledge about screening
    a) Can you please tell me what you know about how a women screens for breast cancer? (If they cannot provide any information, prompt for mammography, breast self-exam and clinical breast examination and provide respondent with the patient education screening brochures then skip to question 2c)
    b) Can you describe these to me (prompt for mammography, breast self-exam, clinical breast examination; prompt for their definition of these three methods, how they would describe what is done)
    c) How often do you think a woman your age should go for a mammography?
    d) How often do you think a woman should do breast self-examination?
    e) How often do you think a woman your age should go for a clinical breast examination?
    f) Please describe for me how much you trust the medical community to help you avoid breast cancer. Do you think medical professionals can help you avoid breast cancer? Why or why not?

3) Their own experiences with screening

a. Can you describe for me your experiences with mammography? Can you describe for me your experiences with breast self-examination? Can you describe for me your experiences with clinical breast examination?

b. Tell me about a typical visit to get a mammography (Skip this question if respondent indicates that they have never gone for a mammography and pick up at breast self exam query; if they have a history of mammography, prompt for information regarding access to mammography, any problems getting or keeping appointments for a mammography, where they usually go for a mammography)

c. Thinking about your past experiences getting a mammography, what was the experience like?

d. Describe any concerns you have with getting a mammography.

e. Why did you have the mammography done?

f. How did you know it was time to go for a mammography?

g. Some women do not go for mammography screening. Can you think of any reasons that may keep a woman from getting this test?

h. What kind of things would keep you from going for a mammography?

i. Please describe for me anything that makes you uncomfortable about having a mammography.

j. Do you feel you know how to correctly do a breast self-exam?

k. Talk to me about how comfortable you are doing this exam.

l. How often do you do this exam? (If they do not do it very often, ask them to explain why)

m. Has anyone ever showed you the correct way to do this exam? Would you be interested in that information? Why?

4. Attitudes about screening

a) Do you think screening is an important way of detecting breast cancer? Why or why not?

b) Do you think screening can save lives? Why or why not?

c) Do you think most women go regularly for screening? Why or why not?

d) Please describe for me any advantages you see to going regularly for screening.

e) Please describe for me any disadvantages you see to going regularly for screening.

f) Do you think that certain types of screening are more important to do than others? Explain.

g) What would make you more likely to screen for breast cancer?

h) What would make you less likely to screen for breast cancer?

5. Screening Education

a) Would you be interested in receiving information from me on screening from the American Cancer Society?

b) What type of information would you be interested in?

c) Would you like to receive a referral from me for a mammogram?

d) Has speaking to me today about breast cancer screening made you aware of any fears or concerns you might have?

Appendix B: Qualitative Interview Piloting

Three women over the age of 50 volunteered to be interviewed by the principal investigator for the purpose of piloting the interview protocol. All women were Caribbean-American and worked in the PI's community as in-home childcare providers. All interviews took place in the residences where they are employed. They all reside in a Caribbean-American neighborhood in a New York City borough. They each voiced that they did not want the interview recorded, so notes were taken as the interviews unfolded. Each respondent was instructed to let the interviewer know when a question was either unclear or did not address their experiences with breast cancer screening. Each respondent was screened to exclude anyone who had a personal or family history with breast cancer. What follows is a summary of my comments.

Interview #1: This 54-year-old female from St. Lucia was quite outgoing and well spoken. The respondent indicated that most of the questions were clear and seemed appropriate to the purpose of the interview. She had substantial knowledge regarding mammography and breast self-exam, but had never gone for a clinical breast exam and reported not knowing that this was a common practice. She reported that she was a little uncomfortable talking about breast self-exam and joked that she was equally uncomfortable performing the exam. She reported that she did it, but not very often and felt she was probably not doing it correctly. She reported that question 3a ("Can you describe for me your experiences with breast cancer screening") seemed a little vague and she was not sure exactly what I was asking until I provided her with certain prompts. I asked if any of the questions made her uncomfortable. She reported that she felt a little uncomfortable admitting that she wasn't screening according to medical guidelines and actually thought for a moment about lying to me. This addresses the social desirability assumption that respondents may

feel inclined to tell the interviewer what they believe the interviewer wants to hear and has implications for the validity of the interview data. It might be helpful if the interviewer prefaces the start of the interview with a brief statement about the need for truthful responses and the respondent's right to not answer any questions they feel uncomfortable about. The interview lasted a total of 42 minutes and all questions in the protocol were addressed.

Interview #2: The second respondent was a 58-year-old female from Jamaica. She was well spoken but initially a little shy. I prefaced this interview with the statements referred to in the above paragraph. In many cases, questions were answered in yes/no format, and further prompts were needed to solicit richer information. The respondent reported not liking question 2a ("Do you know the three ways that women can screen for breast cancer?") as she felt "like you are giving me a test or something". Based on this response, that question has since been revised to ask "Can you please tell me what you know about how a women screens for breast cancer?" Question 3a ("Can you describe for me your experiences with breast cancer screening?") elicited an answer that addressed mammography solely. It appears that the interviewer should be ready to prompt for information related to breast self-exam and clinical breast examination if necessary. To question 4b ("Do you think that screening can save lives?") she reported being unsure as "some things are just out of our control". She alluded to more of a reliance on her faith than on the medical community. It is believed by the researcher that this may be a recurring theme during data collection. Based on her answer it was decided to add Question f to the third section of the protocol ("Please describe for me how much you trust the medical community to help you avoid breast cancer? Do you think medical professionals can help you avoid breast cancer? Why or why not?). This interview lasted 34 minutes and it was felt by the researcher that not as much information was elicited from the respondent as had been elicited during the first interview.

Interview #3: The final interview took place with a 50-year-old female from Jamaica. She appeared a little distracted at the start of the interview, and was asked if she might want to reschedule with the investigator. She reported being a little tired but wanted to go on with the interview nonetheless. Like the first respondent, she reported that question 3a was "not clear....I don't know what you want me to say". It appeared that prompting for the three forms of breast cancer screening would be necessary during actual data collection. Once I restated the initial question into three separate questions (i.e., "Can you describe for me your experiences with mammography?"), she was able to provide rich information for each screening modality. Based on this approach, it was decided that this question would be asked as three separate questions during actual data collection. Like the first respondent, she reported feeling a little uncomfortable talking about her experiences with breast self-exam. I asked if she was uncomfortable enough that she did not want to talk about it. She laughed and said "no, it doesn't make me *that* uncomfortable". The researcher is aware now that soliciting this information may be tricky. Respondents must be made aware at the onset that they can refuse to address any questions that make them too uncomfortable. At the same time, while both women reported being a little uncomfortable with this line of inquiry, they proceeded to answer the question nonetheless and provided a rich narrative response. This interview lasted almost 50 minutes.

Summary of three interviews: It appears that for the most part, all questions (with the exception of 3a) are stated clearly. Question 3a has since been modified as noted above. For the most part, the researcher was able to conduct each interview within the 40-45 minute timeframe hoped for. Each respondent reported the interview did not appear to take that long and that they were not tired or bored with it by the end. Each respondent reported wanting to receive any patient-education material I had brought along with me and left the interview with several

brochures. When asked at the end of the interview if talking about breast cancer screening had made them aware of any fears or concerns they might have, each said that speaking with me had made them aware that they are probably not practicing all screening modalities according to medical guidelines. Respondent #1 stated, "It makes you think, should I be doing more?" The researcher needs to be aware that by participating in this interview protocol, respondents risk coming away with conscious fears and concerns about breast cancer and breast cancer screening. As such, it is vital that the researcher be ready to provide the respondents with educational material (i.e., brochures) and access to screening referrals. Dr. Montgomery has already stated that he would be able and willing to facilitate referrals and the investigator has compiled the appropriate education material.

Appendix C: All Quantitative Instrumentation

Code ID: _____ **Date:** _____

Clinician ID: _____

Individual Information Sheet: Demographics and Access to Care Survey

Respondent Source

Current dental clinic patient (receiving dental care) _____

Dental screening patient (treatment not yet begun) _____

Emergency dental patient _____

1. Date of Birth _____ Age _____

2. Place of Birth _____

3. Where do you currently live? _____

4. How long have you lived there? _____

5. How long have you lived in the United States? _____

6. Would you identify your ethnicity as:

African-American _____

Caribbean (state which Island) _____

If not, other (specify) _____

7. Is English your Second Language (ESL) Yes _____ No _____

8. What other languages do you speak? _____

9. When you speak, what is your primary language? _____

10. When you write, what is your primary language? _____

11. When you read, what is your primary language? _____

12. What is your main source of news? _____

13. What are your main sources of information about your community? _____

14. What are your main sources of information about the services in your community?

_____

15. How do you know where to go for medical services?

_____

16. What is your marital status?

Single (never married) _____ Divorced _____
Married _____ Widowed _____
Separated _____

17. How many children do you have? _____

18. Number of births: _____

19. What is your Religious affiliation? _____ _____

I will read you a statement. Please pick the choice you most agree with:

20. I consider myself to have a very strong religious faith:

Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

21. I am a very spiritual person:

Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

22. What is your present occupation? _____

23. How long have you done this work? _____

24. Indicate your highest level of education:

Grades 1-8_____ Some College _____
Some High School _____ College Graduate _____
High School graduate _____ Graduate school _____
Technical or vocational school _____

25. What is the number of people living in your <u>immediate</u> household? _____

26. Now I am going to ask you who they are:

Spouse/partner _____
Children (how many) _____
Dependent children _____
Non-dependent children _____
Parents (how many) _____
Other (specify) _____

27. What is the total amount of your individual monthly wages, not including benefits (check off choice that applies):

$0.00 - $500.00 _____
$501.00 - $1,000.00 _____
$1,001.00 - $1,500.00 _____
$1,501.00 - $2,000.00 _____
$2,001.00 - $2,500.00 _____
$2,501.00 - $3,000.00 _____
More than $3,000.00 _____

28. What is the total amount of your household monthly wages, not including benefits? (check off choice that applies)

$0.00 - $500.00 _____
$501.00 - $1,000.00 _____
$1,001.00 - $1,500.00 _____
$1,501.00 - $2,000.00 _____
$2,001.00 - $2,500.00 _____
$2,501.00 - $3,000.00 _____
$3,001.00 - $3,500.00 _____
$3,501.00 - $4,000.00 _____
More than $4,000.00 _____
Don't know _____

29. Do you receive any of the following benefits?

Retirement or pension benefits _____
Social Security Pension (SS) _____
Public assistance _____
SSI _____
Social Security Disability (SSD) _____
Veteran's Benefits _____
Unemployment Insurance _____
AFDC _____
Medicaid _____
Medicare _____
Any other benefits (specify) _____

30. Do you have health insurance at this time? Yes _____ No _____

(a) If yes, what kind _____
(b) If yes, who is the insured? _____
(c) If yes, how long in this plan _____

31. Think back over the last year about the different medical services you received. In the last year have you:

Seen a doctor	Yes _____	No _____
Had a physical examination	Yes _____	No _____
Seen a gynecologist	Yes _____	No _____
Seen a dentist	Yes _____	No _____
Seen a nurse practitioner	Yes _____	No _____
Seen a healer	Yes _____	No _____
Seen a chiropractor	Yes _____	No _____
Seen an acupuncturist	Yes _____	No _____
Seen a homeopathic	Yes _____	No _____
Seen an herbalist	Yes _____	No _____
Seen a hypnotist	Yes _____	No _____

32. Overall, how satisfied are you with the medical services you receive:

Very satisfied _____
Satisfied _____
Somewhat satisfied _____
No Opinion _____
Somewhat dissatisfied _____
Dissatisfied _____
Very dissatisfied _____

33. What is the biggest problem in getting a doctor's appointment?

(Check all that apply)
None _____
Finding a doctor _____
Contacting the medical office _____
Getting through to someone who can help with appt. _____
Getting an appointment that fits my schedule _____
Other (detail) _____

34. What is the biggest problem in keeping a doctor's appointment?

(Check all that apply):
None _____
Sudden change in schedule _____
Getting to the medical office _____
Finding childcare _____
Other _____

35. What is the biggest problem when attending the doctor's appointment?

(Check all that apply)
None _____
Waiting to be seen by the medical professional _____
Being sent to other doctors for additional evaluation _____

Being sent for additional lab work _____
Filling out all the paperwork _____
Problems with health insurance _____
Paying for the medical services _____
Other (describe) _____

36. Do you have any problems with your health coverage? Yes ___ No ____
(Please describe)

_____
_____
_____

37. Do you have a chronic illness? Yes _____ No _____

38. What type of chronic illness do you have? (List all) _____

39. Do you take medication at the present time? Yes _____ No _____

40. What kind of medications do you take for your chronic illness? (List all)

_____
_____

41. How satisfied are you with the medical care you get for chronic disease?

Very satisfied _____
Satisfied _____
Somewhat satisfied _____
No opinion _____
Somewhat dissatisfied _____
Dissatisfied _____
Very dissatisfied _____

(If respondent provides narrative, list it here):

_____
_____

42. What are some factors that might keep you from using medical services when you need them? List any that apply.

_____
_____
_____

43. What are some factors that encourage you to use medical services when you need them? List any that apply.

_____
_____
_____

44. What do you like most about the medical care you receive?

_____

_____

45. What do you like least about the medical care you receive?

_____

_____

46. How did you get to your appointment today?

Drove myself _____ Got a ride _____
Cab _____ Walked _____
Bus _____ Ambulette _____
Train _____ Other _____

47. How do you usually get to your medical appointments?

Drove myself _____ Got a ride _____
Cab _____ Walked _____
Bus _____ Ambulette _____
Train _____ Other _____

48. How much average time does a medical appointment take from the moment you leave for the appointment till the moment you return? _____

49. Besides the cost of the medical visit, on average, what is the financial cost for you to get to an appointment? (Include carfare, bus or train fare, childcare, lost time from work)

_____

50. Do you usually travel to medical appointments?

From your home _____
From your job _____
Other (specify) _____

51. Do you go to different locations for different medical services? Yes _____ No _____

52. How often do you go to different locations for different medical services?

Always _____
Often _____
Sometimes _____
Rarely _____
Never _____

53. How often to you have to go to different locations for different services?

Never _____ Rarely _____ Sometimes _____
Often _____ Always _____

54. Do you know if there is a health clinic within close distance to you? Yes _____ No _____

55. If yes, how often do you use the services there?
Most of the time _____
Some of the time _____
Rarely _____
Never _____

56. How would you rate your travel to and from medical appointments?
Very easy _____
Easy _____
Difficult _____
Very difficult _____

57. Do you have any limitations or handicaps that keep you from getting medical care when you need it? Yes _____ No _____ If yes, explain:

_____

_____

Please tell me how much you agree with the following statements:
58. I trust my health care providers to give me the proper medical care:
Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

59. I trust my health care providers when they make suggestions on how I can best take care of myself:
Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

60. I trust my health care providers when they prescribe medication for me:
Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

(Please fill in the blank for the next three items)
61. I would feel better about my medical care if:

_____

_____

62. I would feel better about my medical care if my health care provider would:

_____

_____

63. I would feel better about my medical care if my health insurance carrier would:

_____

_____

64. When my health care provider prescribes medication for me, I

(a) Closely follow their instructions:
Always_____ Usually _____ Sometimes _____ Never _____

(b) Fill my prescription:
Always_____ Usually _____ Sometimes _____ Never _____

(c) Take the entire prescription
Always_____ Usually _____ Sometimes _____ Never _____

(d) Trust that the medication will make me feel better:
Always_____ Usually _____ Sometimes _____ Never _____

(e) Worry that the medication will have side effects:
Always_____ Usually _____ Sometimes _____ Never _____

(If respondent provides narrative, list it here):

_____

_____

65. When my health care provider makes recommendations about how I can improve my health, I:

(a) Closely follow their instructions:
Always_____ Usually _____ Sometimes _____ Never _____

(b) Agree with their recommendations:
Always_____ Usually _____ Sometimes _____ Never _____

(c) Understand their recommendations:
Always_____ Usually _____ Sometimes _____ Never _____

(d) Trust their recommendations:
Always_____ Usually _____ Sometimes _____ Never _____

(If respondent provides narrative, list if here):

_____

_____

66. When I do follow my health care providers' recommendations, it is usually because:

_____

_____

_____

67. When I do not follow my health care providers' recommendations, it is usually because:_____

_____

_____

68. In the last 12 months, how many times did you go to the emergency room for medical care:

None _____ Fill in number of times _____

69. In the last twelve months, not counting visits to the emergency room, how many times have you gone to a doctor's office or clinic:

List number of times _____

70. In the last twelve months, my health insurance plan caused delays in my health care:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly Disagree _____

71. When I go to see a doctor they usually explain things to me in a way that I can understand:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly Disagree _____

72. When I go to see a doctor they usually treat me with respect:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly Disagree _____

73. When I go to see a doctor, the office staff usually treats me with respect:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly Disagree _____

_____

74. When I go see a doctor they usually listen carefully to what I have to say:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly Agree _____

CODE ID: _____ Date _____

Intent to Breast Cancer Screen

We are very interested in learning about your thoughts on breast cancer screening. Please respond to each statement honestly. There are no right or wrong answers. List your level of agreement with each statement using the following scale:

1 Strongly Disagree	2 Disagree	3 Not Sure	4 Agree	5 Strongly Agree

1) I plan on having a mammogram sometime next year. _____

2) I plan on performing breast self-examination sometime next year. _____

3) I plan on performing breast self-examination several times next year. _____

4) I haven't really thought about having a mammogram this coming year. _____

5) I plan on performing breast self-examination once a month. _____

6) I have no intention of scheduling a mammogram this coming year. _____

7) I haven't really thought about performing breast self-examination in the future. _____

8) I plan on having a breast examination done by a health care professional sometime next year. _____

9) I have no intention of performing breast self-examination in the coming year. _____

10) I haven't really thought about scheduling a breast examination in the future. _____

11) I have no intention of scheduling a breast examination in the coming year. _____

Quick Patient History: Criteria for Inclusion/Exclusion from Study

1) Age
2) Health insurance
   Yes _____ No _____
   Type _____

3) Health status
   Excellent_____ Good_____ Fair _____ Poor _____

4) Chronic health problems (list):

_____
_____
_____

5) Chronic disease (list):

_____
_____
_____

6) Personal history of breast cancer:
   Abnormal mammography _____
   Breast cancer diagnosis _____
   If so, when _____

7) Family history of breast cancer:
   Which family member(s): _____
   Abnormal mammography _____
   Breast cancer diagnosis _____
   If so, when _____
   Survivor or Mortality (date) _____

8) Ethnic background:
   Country of origin _____
   Identify as: African American _____
   Caribbean Amerian _____
   If so, which region _____
   Other _____

9) Screening history:
   Breast self-exam: Y____ N _____ Frequency _____ Last done _____
   Clinical self-exam: Y____ N _____ Frequency _____ Last done _____
   Mammography: Y____ N _____ Frequency _____ Last done _____

Code ID: _____ Date: _____

Screening Beliefs Scale
(Champion & Scott, 1997)

Please list your level of agreement with each statement using the following scale:

1	2	3	4	5
Strongly Disagree	**Disagree**	**Not Sure**	**Agree**	**Strongly Agree**

Mammogram:

1) Having a mammography will help me find breast lumps early. _____
2) I am afraid to find out there is something wrong when I have a mammogram. _____
3) I cannot remember to schedule an appointment for a mammogram. _____
4) Having a mammogram will decrease my chances of dying from breast cancer. _____
5) Having a mammogram costs too much money. _____
6) People doing the mammogram are rude to women. _____
7) If I find a lump early through mammogram my treatment for breast cancer may not be as bad. _____
8) Having a mammogram would expose me to unnecessary radiation. _____
9) Having a mammogram can be too embarrassing. _____
10) Having a mammogram is the best way for me to find a very small breast lump. _____
11) There are other things in my life more important than getting a mammogram. _____
12) Having a mammogram would take too much time. _____
13) It is difficult to get transportation for a mammogram. _____
14) Having a mammogram can be painful. _____
15) I don't know how to go about scheduling a mammogram. _____
16) It is difficult to get childcare so I can get a mammogram. _____
17) I am afraid to have a mammogram because I don't understand what will be done. _____
18) Getting a mammogram every year (every other year) is a high priority for me. _____

Breast self-examination:

1) When I do breast self exam I am doing something to take care of myself. _____
2) Breast self exam is embarrassing to me. _____

3) I do not feel I can do breast examination correctly. _____

1	2	3	4	5
Strongly Disagree	**Disagree**	**Not Sure**	**Agree**	**Strongly Agree**

4) If I find a lump early through breast exam, my treatment for breast cancer may not be as bad. _____

5) Breast self-exam is not necessary if I have a routine mammogram. _____

6) Breast self-exam takes too much time. _____

7) My breasts are too large for me to complete breast self-examination. _____

8) Completing breast self-exam each month may help me to find breast lumps early. _____

9) It is hard to remember to do breast self-exam. _____

10) Breast self-exam is not necessary if you have a breast exam done by a health care provider. _____

11) My breasts are too lumpy for me to perform breast examination correctly. _____

12) Completing breast self exam each month may decrease my chances of dying from breast cancer. _____

13) Doing breast self-exam will make me worry that something is wrong with my breast. _____

14) I don't have enough privacy to do breast self-examination. _____

15) I have other problems more important than doing breast self-examination. _____

16) I know how to perform breast self-examination. _____

17) I would be able to find a breast lump the size of a pea. _____

18) I can perform breast self-examination correctly. _____

19) I could find a breast lump by performing breast self-examination. _____

20) I am able to find a breast lump which is the size of a quarter. _____

21) I am able to find a breast lump which is the size of a dime. _____

22) I am sure of the steps to follow for doing breast self-examination. _____

23) I would be able to tell something is wrong with my breasts when doing breast self-examination _____

24) I am able to tell something is wrong with my breasts by looking in the mirror. _____

25) I can use the correct part of my fingers when examining by breasts. _____

Code ID: _____ Date: _____

Breast Cancer Screening Practices

(Saint-Germain & Longman, 1993)

We are very interested in learning about your experiences with breast cancer screening. Please answer each question honestly. There are no right or wrong answers to these questions.

1) Have you ever had a mammogram ? Yes_____ No _____

2) Have you had at least two mammograms? Yes _____ No _____

3) Have you had at least three mammograms? Yes _____ No _____

4) Have you had two mammograms in the past two years? Yes _____ No _____

5) Have you had three mammograms in the past three years? Yes _____ No _____

6) Have you ever had a breast examination by a health care provider? Yes _____ No _____

7) Have you had a breast examination in the last year? Yes _____ No _____

8) Have you ever done a breast self-examination? Yes _____ No _____

9) Did you perform a breast self-exam in the last year? Yes _____ No _____

10) On average, how many times per year do you perform breast self-examination. _____

Applying Q Methodology to Breast Cancer Screening Research: A new Theoretical and Statistical Approach to Quatifying the Subjective Experiences of Undeserved Women

By

Kathryn C. LaSorsa and Theresa J. Jordan Ph.D.

The third Era of Hope meeting for the Department of Defense (DOD) Breast Cancer Research Program (BCRP)

September 25-28, 2002

Orange County Convention Center in Orlando, Florida

APPLYING Q METHODOLOGY TO BREAST CANCER SCREENING RESEARCH: A NEW THEORETICAL AND STATISTICAL APPROACH TO QUANTIFYING THE SUBJECTIVE EXPERIENCES OF UNDERSERVED WOMEN

Kathryn C. LaSorsa and Theresa J. Jordan, Ph.D.

New York University

nyukat@aol.com

Attempts to increase women's participation and adherence to breast cancer screening have tended to use broadly applied health models to examine predetermined barriers and facilitators to screening. These studies have demonstrated equivocal findings for low-socioeconomic status Black women and seem to indicate that existing models are not sensitive to the life experience and decision-making practices of this population. Low socioeconomic-status Black women develop a frame of reference regarding breast cancer screening that emerges from their specific sociocultural context. Understanding and systematically studying this subjective condition may be a useful alternate approach to modeling the phenomenon of screening among this cohort. Alternative techniques are required to systematically study the subjective experiences of Black women and the impact of these experiences on screening adherence.

Q-methodology is a conceptual framework that allows the examination and quantitative analysis of subjective data, with the goal of preserving the respondent's frame of reference. This method follows a particular logic of inquiry and applies technical specificities that allow us to go beyond a priori barriers and benefits to breast cancer screening. Black women's actual experiences, perceptions and attitudes can then inform a model of the screening phenomenon.

Qualitative interviews were conducted to determine the factors that are either encouraging or discouraging cancer screening participation.. These factors, or Q-statements, are the stimuli that made up the Q-sort instrument. Respondents systematically rank ordered these stimuli according to a condition of instructions. Q-statements were rank-ordered along a five-point continuum of "Strongly encourages me to screen" to "Strongly discourages me from screening". In Q methodology, variables are the individuals performing the Q-sorts, not the Q-sample statements. Viewpoints regarding the phenomenon of breast cancer screening are modeled in the Q-sorts. Data analysis involves the intercorrelation of the N Q-sorts. Factor analysis examines this correlation matrix to determine how many basically different Q-sorts, or factors, are demonstrated. Those individuals significantly correlated with a given factor are assumed to share a common perspective. This approach allows the systematic study of the barriers and benefits to screening that have been identified by participants. The factors have emerged from them as valid operational definitions of their subjective point of view.

This paper will present preliminary findings from the qualitative data collection, the design of the Q-sort statements, the participants' responses to the Q-sort and an analysis and interpretation of correlational and factor analytic procedures.

The U.S. Army Medical Research and Materiel Command under DAMD17-99-1-9317 supported this work.

New York University
A private university in the public service
Office of Sponsored Programs
665 Broadway, Suite 801
New York, NY 10012-2331
Telephone: (212) 998-2121
Fax: (212) 995-4029
E-mail: osp.agency@nyu.edu

September 12, 2012

Maria Anthony
Contract Specialist
U.S. Army Medical Research Acquisition Activity (USAMRAA)

Subject: DAMD17-99-1-9317
An Investigation of Facilitative and Inhibitory Variables Impacting Breast Health

Dear Ms. Anthony,

We are writing in response to your email notice of September 6 regarding a delinquent reports, and on behalf of New York University, the grantee organization for the subject expired CDMRP Predoctoral Traineeship awarded in October, 1999, to Kathryn LaSorsa, then PhD candidate in NYU's Steinhardt School of Education, Health, Nursing and Arts Professions, under the mentorship of Professor Theresa Jordan.

Please note that this is the only grant among the four identified in your email which was made to NYU. The other three grants were made to the NYU School of Medicine, a separate federal grantee organization.

We are investigating the matter of the outstanding annual report as thoroughly as we can. This Office and the Dean for Research at the Steinhardt School had tried unsuccessfully to reach both Ms. LaSorsa and Professor Jordan immediately following receipt of Joshua Disbennett's notice regarding an overdue final report for the grant on August 2nd. In the interim we had also attempted to locate Ms. LaSorsa at the New York City Department of Health and Mental Hygiene, where she was at one time employed. Since receiving your email we have taken the additional steps of reaching out to Professor Jordan's chair, who has been helpful in assembling related information. In addition, we have sent a letter via courier to to Ms. LaSorsa at her last known address (copy attached) with a prepaid return envelope (in the event she might yet provide followup documentation).

Unfortunately, given the time that has elapsed since expiration of the grant, there are few records which remain in official University records to help us to sort out what occurred at conclusion of the project. We have learned that Ms. LaSorsa

and Professor Jordan presented results of the project at a September 2002 conference (abstract attached). We know that she wrote to the Dr. Jordan and the Dean on February 12, 2004, indicating that she had submitted her Annual Report to DOD that day (see email attached). We also know that she withdrew from the PhD program in October of 2004 due to personal problems, but completed an MA in Psychological Measurement and Evaluation in the Spring of 2005 and has not registered since. Her colleagues in Steinhardt believe it unlikely that she made any further progress on the project between the February 2004 report and the date of her withdrawl from the doctoral program, given other events in her life at the time.

The University greatly appreciates the government's generous support for this former student, and we sincerely regret that we have no further information at this time to complete your files. Please be assured that any further information which comes to light will be forwarded to your attention.

Respectfully,

Richard Louth

Richard L. Louth
Director

attachments

Addendum: February 15, 2013

The University has been unable to locate PI Kathryn LaSorsa, who was last affiliated with NYU in 2005, at which time she graduated with an MA. As she dropped out of the Ph.D. program, no dissertation was filed with the University. We have also tried repeatedly but failed to connect with her faculty advisor, Dr. Theresa Jordan, who is retired. We can confirm that a final Financial Status Report was filed with DOD in April of 2004.

New York University
A private university in the public service

Richard Louth
Director, Office of Sponsored Programs
665 Broadway, Suite 801
New York, NY 10012-2331
Telephone: (212) 998-2121
Fax: (212) 995-4029
E-mail: osp.agency@nyu.edu

September 6, 2012

Kathryn Lasorsa
1869 Ocean Parkway
Brooklyn, NY 11223

Subject: DAMD17-99-1-9317
An Investigation of Facilitative and Inhibitory Variables Impacting Breast Health

Dear Ms. Lasorsa,

The Department of Defense has contacted the University several times with regard to an outstanding technical progress report which they claim is due them under the subject grant, which expired some years ago. This grant was awarded in support of your research as a graduate student in the Steinhardt School under the sponsorship of Professor Theresa Jordan.

As indicated in DOD's latest notice attached, the agency is threatening to withhold payments on existing NYU grants and/or decline to issue a new pending award unless the University fulfills the reporting requirement, and it is absolutely within their authority to do so. It is therefore imperative that we respond as soon as possible.

According to Steinhardt's records, the address above is the last contact information for you currently on file, hence our effort to reach you by mail. So much time has transpired since your award expired that we can neither deny or verify the agency's claims, and we will need your cooperation to provide a substantive response.

Can you provide any documentation to demonstrate that progress was reported to the agency during and/or at conclusion of the project ? Did you publish or present any of your findings which we can share with DOD? In lieu of specific, grant-related data or reports, did you produce any student thesis, papers or other written materials that describe the results of the project?

We would very much appreciate your help to complete and close DOD's records regarding this grant. Please contact me to discuss it.

Sincerely,

Richard

cc: Professor Theresa Jordan
Attachment

Date: Thu, 12 Feb 2004 16:26:22 -0500
From: Perry Halkitis <perry.halkitis@nyu.edu>
Subject: Fwd: Re: DOD report
To: Karen Jenkins <kdj1@nyu.edu>
X-Mailer: iPlanet Messenger Express 5.2 HotFix 1.15 (built Apr 28 2003)
X-Accept-Language: en
Priority: normal
Original-recipient: rfc822;kdj1@mail.nyu.edu

FYI
File this one.
Perry N. Halkitis, PhD
Assistant Professor & Interim Chair
Department of Applied Psychology
New York University
Co-Director Center for HIV Educational Studies & Training (CHEST)
239 Greene Street East 537G
NY, NY 10003
212.998.5373--NYU
212.206.7919 x227--CHEST
212.995.3654--fax NYU
212.206.7994--fax CHESTReturn-path: <Nyukat@aol.com>
Received: from mx4.nyu.edu (MX4.NYU.EDU [128.122.108.105])
by mail.nyu.edu (iPlanet Messaging Server 5.2 HotFix 1.15 (built Apr 28 2003))
with ESMTP id <0HSZ00BV8NUEDG@mail.nyu.edu>; Thu,
12 Feb 2004 15:35:02 -0500 (EST)
Received: from imo-m26.mx.aol.com (imo-m26.mx.aol.com [64.12.137.7])
by mx4.nyu.edu (8.12.10/8.12.9) with ESMTP id i1CKYwQJ010690; Thu,
12 Feb 2004 15:34:59 -0500 (EST)
Received: from Nyukat@aol.com by imo-m26.mx.aol.com (mail_out_v36_r4.12.)
id p.1ef.18e67236 (4426); Thu, 12 Feb 2004 15:34:53 -0500 (EST)
Date: Thu, 12 Feb 2004 15:34:53 -0500 (EST)
From: Nyukat@aol.com
Subject: Re: DOD report
To: theresa.jordan@nyu.edu, perry.halkitis@nyu.edu
Message-id: <1ef.18e67236.2d5d3d6d@aol.com>
MIME-version: 1.0
X-Mailer: 8.0 for Windows sub 6021
Content-type: multipart/alternative;
boundary=part1_1ef.18e67236.2d5d3d6d_boundary

Terry & Perry,

I submitted the DOD Annual Report today as well as reconnected both with the dental clinic and NYU's Office of Sponsored Research via email. I know that my time here in PA with my mom is almost over. I made it clear to all that in the coming weeks, I want to get back to data collection. Of urgent importance right now is my IRB reapproval from NYU. I am almost finished with that report and will be submitting to my contact person as soon as I hear back from her.

The grave nature of those ill in my family, together with their out-of-state locations has made any academic efforts impractical these last months. I have fretted over this many times,

but have been powerless to do anything about it.

Honestly, it's been a very difficult time here...pancreatic cancer is a bumpy ride of lingering pain and suffering. I hope every day that my time here with my mom has helped her in some way face all of this with just a little more comfort and less fear. I also know that when this chapter is over, I must get back to whatever I need to do to fulfill my responsibility to the DOD and my degree. I will keep you informed of any movement.

Best,
Kathy LaSorsa